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Women's Illness Experience With Interstitial Cystitis/Bladder Pain Syndrome: A Scoping Review

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ABSTRACT

What is known about the illness experience of women with Interstitial Cystitis/Bladder Pain Syndrome? Interstitial Cystitis/Bladder Pain Syndrome is a rare, chronic condition of the urinary bladder that affects women nine times more often than men. Without appropriate treatment, it can severely impact quality of life and psychosocial well-being. Achieving a deeper, gender-specific understanding of the illness experience is crucial for empowering women to develop effective self-management and coping strategies. Existing scientific literature presents a fragmented perspective on patients' experiences. To provide a comprehensive overview of the available evidence, a scoping review was conducted following the JBI methodology, guided by the Illness Constellation Model by Morse and Johnson. Out of 1206 hits, 25 studies met the inclusion criteria, varying in research design, methodological reporting precision, and inclusion criteria. Most of the evidence referred to the Stage of Striving to Regain Self, with no results clearly addressing the Stage of Uncertainty. All results were based on the perspectives of affected women, with four studies including expert opinions. However, none of the studies included direct information from family members, whose perspectives were inferred indirectly. The evidence highlighted the physical, psychosocial, and cognitive challenges experienced throughout the illness. Women with Interstitial Cystitis/Bladder Pain Syndrome face significant challenges that affect their family life, relationships, and career, though research on family interactions is limited. Well-being is closely linked to self-management, partner support, and coping mechanisms, but what constitutes effective self-management from the women's perspective remains unclear. The review calls for more qualitative research, methodological transparency, and improved support and awareness in healthcare practices. The Illness Constellation Model appears insufficient to fully capture the experiences of individuals with Interstitial Cystitis/Bladder pain syndrome, particularly the recurring nature of uncertainty throughout the illness trajectory. Future research should aim for a deeper understanding of successful self-management and coping strategies, including the role and perspectives of family members.

1 | Rationale

Interstitial cystitis (IC)/bladder pain syndrome (BPS) is defined as persistent or recurrent chronic pelvic pain, pressure or discomfort perceived to be related to the urinary bladder accompanied by at least one other urinary symptom such as an urgent need to void or urinary frequency [1]. The aetiology of IC/BPS is still unknown. Basically, men and women of all ages can be affected. The prevalence is highest in middle-aged persons. The Guideline Group S2K Guideline for IC indicates for Germany, Austria and Switzerland that women are nine times more frequently affected by IC/BPS than men [2].

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Summary

- What is known about this topic
  - Interstitial Cystitis/Bladder Pain Syndrome can severely impact quality of life and psychosocial well-being, with no universally effective therapy known.
  - A gender-specific perspective on the condition throughout the illness trajectory is needed to understand and effectively support those affected.
- What this paper adds
  - This review provides a model-guided overview of the illness experience of women with Interstitial Cystitis/Bladder Pain Syndrome over the course of the illness trajectory.
  - It was demonstrated that women with Interstitial Cystitis/Bladder Pain Syndrome can enhance their well-being through effective self-management, partner support, and coping mechanisms, but what constitutes effective self-management from their perspective requires further research.
  - The review calls for more qualitative studies with methodological transparency.

A prevalence in women of 500/100.000 and a prevalence in men of 8–41/100.000 is estimated [2]. IC/PBS has a long period of uncertain diagnosis and can easily be confused with other diseases, for exapmle with fibromyalgia [2]. The extent to which there are unreported cases is not known, although it can be assumed that those affected, and their problems remain hidden.

Due to the gender-specific symptomatology of IC/BPS, including dyspareunia and menstrual cycle-related symptom variation, IC/BPS must be understood in a gender-specific context.

IC/BPS is considered incurable [3]. The treatment of IC/BPS includes behavioural therapy, physiotherapy, oral medications, complementary medicine, intravesical therapy, transurethral procedures, surgical therapy, and rehabilitation [2–5]. Professional scientific societies are revisiting terminology, aetiology, and treatment protocols, whereas international guidelines offer recommendations of varying detail, primarily based on limited evidence and empirical knowledge [6]. There is no universally recognised therapeutic approach deemed effective for all cases [5]. Instead, therapeutic strategies are tailored individually, with the affected person's self-management and coping strategies serving as the foundation for successful treatment [2, 5, 7]. A new understanding of the disease is necessary and expected.

Grypdonck emphasises that chronic illness, and IC/BPS is one of them, affects family members as much as the chronically ill person themselves [8], with 'family' being defined by Schnepp, Fringer and Budroni as 'what it means to the person affected' [9].

Furthermore, Grypdonck explains that care for the chronically ill can only be effective if it is provided from the family's perspective [8]. It can be assumed that a deeper understanding of the experience of women with IC/BPS and their families during the course of their illness is of particular importance in order to support the individual coping activities in a tailored manner as described by Höhmann, and thus contribute to maintaining the self-determination and independence of those affected [10]. However, such an overview, summarising the illness experience of women with IC/BPS during the course of the illness, is missing.

1.1 | State of Research

The situation of women with IC/BPS is explored in publications of varying methodology and research focus. The majority of these publications focus on symptom assessment and management, diagnostics, or therapeutic approaches [7, 11–13]. Other studies therefore provide fragmentary insights into the illness experience of those affected, as they focus on specific aspects such as the impact of diagnosis [14] or coping with pain [15].

A literature search conducted in March 2024 in MEDLINE (via PubMed) and the Cochrane Library did not identify a scoping review or systematic review that focused on the illness experience of women with IC/BPS.

1.2 | Theoretical Framework

The Illness Constellation Model by Morse and Johnson served as the guiding concept for this scoping review [16].

The model outlines the illness experience as a four-stage process for patients and their families: (1) Stage of Uncertainty, (2) Stage of Disruption, (3) Stage of Striving to Regain Self, and (4) Stage of Regaining Wellness. For women with IC/BPS, the model offers a framework for reconstructing their illness experience, helping to understand how they recognise the condition, access treatment, and work towards regaining well-being. The operationalisations of the four stages are provided in Appendix A.

2 | Aim and Research Question

The objective was to (a) identify, map, and synthesise the available evidence on the illness experience of women with IC/BPS, and (b) identify research gaps. The findings aim to enhance understanding of the affected individuals' experiences and inform treatment teams in optimising care models. The identified research gaps will serve as starting points for further research.

The following research question guided the scoping review:

What is known about the illness experience of women with IC/BPS?

3 | Materials & Methods

To get an overview of the results of primary research, reviews gain immense importance. Initial literature search suggested that little evidence was available on the research question. In

TABLE 1 | Inclusion criteria.

Criteria	Definition
Population	• Women diagnosed with IC/BPS
Concept	• Illness experience
Context	• No limitations
Other	• Methodology: no exclusion • Languages: German and English • Year of publication: no exclusion • Sources: primary research, reviews, professional societies, guidelines, position papers

TABLE 2 | Exclusion criteria.

Criteria	Definition
Population	• Men • Children
Other	• Diagnosis techniques • Surgical techniques • Sources: social media

addition, the interest was to examine how the object of research was investigated. Here, the scoping review method offers a way to develop a synthesis of the state of the research literature on a particular topic (including main concepts, definitions, theories, research gaps), considers different types of publications and does not examine them for their methodological quality [17]. This approach results in a more comprehensive overview, which may not be achievable if methodologically weak publications are excluded. Unlike systematic reviews, scoping reviews do not aim to answer specific, focused questions but instead offer a broad overview of the available evidence [17].

This scoping review followed the methodological framework proposed by Arksey and O'Malley [18] and further developed by the Joanna Briggs Institute [19, 20]. Development and reporting follow the PRISMA-ScR checklist and explanation [21].

In addition to the quantitative analysis of the literature (presented as a graph or map), this scoping review offers an initial, concise summary of the content.

3.1 | Inclusion and Exclusion Criteria

The inclusion criteria are based on the research aim and question and reported by using the PCC mnemonic [20]: Population (P), Concept (C) and Context (C) (Table 1).

Research studies of any methodology are considered a potential source of credible evidence, so no methodology is excluded [19].

To focus the literature search on the affected person perspective, exclusion criteria were defined, which are summarised in Table 2.

3.2 | Search Strategy

Although synonyms and keywords for the first two search components were easy to identify, the term illness experience had to be operationalised. Synonyms, concepts, domains, and dimensions of illness experience were defined by consensus between the authors based on the literature (Table 3). The search strategy was designed to be open and sensitive, aiming to identify and analyse as many relevant publications as possible [22].

3.3 | Literature Search

Five databases were searched: MEDLINE (via PubMed), CINAHL (via EBSCO), Cochrane Library, PSYNDEX (via Livivo) and PsycINFO (via Epistemonikos). Backward citation tracking has been applied to identify additional studies. In addition, the internet resources Google and Google Scholar have been used to find further resources. Guidelines from scientific professional societies were reviewed.

3.4 | Screening the Results

The process of source selection was based on the recommendations of the Joanna Briggs Institute and included three stages of selection based on (a) title, (b) abstract, and (c) full text [20]. The review process was supported by the software RAYYAN, by Rayyan Systems Inc. [23]. Abstract screening was performed based on inclusion and exclusion criteria by three reviewers (anonymised), independently. In case of disagreement, a fourth reviewer (anonymised) was included. Full text screening was performed by the first author, and reasons for excluding full texts were documented (Appendix B). The literature was managed in the software CITAVI version 6.19.1.1 of the Swiss Academic Software GmbH [24].

3.5 | Extracting and Charting the Results

The Illness Constellation Model according to Morse and Johnson was chosen as a guide for mapping the literature (see Appendix A).

Data were extracted and analysed using a category-based analysis protocol, which was initially tested on three studies before being applied to all relevant publications. The purpose of the data extraction was to generate a coherent and descriptive summary of the findings. The extraction fields are shown in Table 4.

4 | Results

A total of 1206 potentially relevant references were yielded from the literature search. Eighty two additional references were identified. Two hundred thirty-two duplicates were removed. Based on the inclusion criteria, 64 references were selected for full text screening. A final sample of 25 references met the inclusion criteria. The screening of the references is shown in the PRISMA flow diagram (Figure 1). The excluded full texts are listed in the additional Appendix A.

TABLE 3 | Search strategy PubMed.

	Women (population)	IC/PBS (population)	(Concept)
Search components/ synonyms/ variations	"Women" [Mesh] OR "Female" OR "Patients" [Mesh]	"Cystitis, Interstitial" [Mesh] OR "Bladder Pain Syndrome" OR "Chronic Interstitial Cystitis" OR "Cystitis, Chronic Interstitial" OR "Interstitial Cystitis" OR "Interstitial Cystitis, Chronic" OR "Painful Bladder Syndrome" OR "IC/BPS" [TIAB]	"Illness experience" OR "experience" OR "experience of illness" OR "sickness experience" OR "disease experience" OR "Patient experience" OR "Lived experience" "experiencing illness" OR "illness perception" OR "Patient reported" [TIAB] OR "Quality of Life" [Mesh] OR "Health Related Quality of Life" [TIAB] OR "illness Behaviour" [Mesh] OR "Sick Role"[Mesh] OR "Activities of Daily Living"[Mesh] OR "Burden" OR "Situation" OR "Suffering" OR "Coping" OR "Adaption, psychological" [Mesh] OR "Stress psychological" [Mesh]

4.1 | Characteristics of the Included Studies

Thirteen studies followed a mixed method design, six studies followed a qualitative research design, and four studies did not provide clear information on the research design and based on expert opinion and a literature review. One study combined a self-report with the results of a quantitative data analysis.

Table 5 shows the country of origin and the study designs of the included publications.

The 25 studies differed in terms of the inclusion and exclusion criteria of the study participants. For example, women who were already in remission [25] or who were experiencing acute emotional distress [26] were excluded.

The results of all publications are based on the perspective of affected women with IC/BPS, four times in combination with expert opinions.

None of the studies included family members. If their views were considered, then only from the perspective of those affected or experts.

4.2 | Narrative Summary of Evidence

Based on the Illness Constellation Modell according to Morse and Johnson [16], the identified evidence on the illness experience of women with IC/BPS and their relatives is briefly summarised below. Due to the allocation of evidence, only three of the four levels of the model are summarised.

Most of the evidence could be categorised in the third stage of the Illness Constellation Model, [10], the Stage of Striving to Regain Self. Ten studies provided information on the Stage of Regaining Wellness. There is no conscious reference to the first stage of the Illness Constellation Model in any of the studies. No results of the 25 included studies could be clearly assigned to the Stage of Uncertainty. Only one of the 25 publications focused exclusively on the diagnosis phase. Figure 2 provides an overview of the study results mapped to the four stages of the Illness Constellation Model.

4.2.1 | Stage of Disruption

Women with IC/BPS face numerous challenges until they receive a final diagnosis. This includes persistently waiting for confirmation while at the same time feeling trivialised, stigmatised, embarrassed and uncomfortable [26–33]. The path to diagnosis is lengthy, takes on average over 2 years and requires consultation with multiple doctors leading to doubt and uncertainty [12, 30, 32, 34]. Misdiagnosis and delays in diagnosis contribute to emotional distress, including anxiety and depression, as symptoms are dismissed or disbelieved, affecting psychological well-being [26–29, 31–33, 35–38]. Despite this, sufferers emphasise the importance of continuing to seek a correct diagnosis [30, 34]. Despite these obstacles, women highlight the importance of persisting in their search for an accurate diagnosis, with support from family and psychotherapists playing a key role in their self-advocacy [27, 30, 34].

4.2.1.1 | Receiving a Diagnosis. The diagnosis of IC/BPS has different effects on those affected: Some feel empowered and more in control, whereas others experience negative consequences such as stigmatisation by healthcare providers or feelings of despair when they realise there is no cure [14, 32]. Although for some the diagnosis brings relief, hope, and reassurance, it can also be stressful and lead to feelings of disability and frustration with the treatment options available [14, 32, 39].

Those affected are in need of a meaningful illness narrative [40].

4.2.1.2 | Finding the Right Initial Treatment. Treatment experiences are described differently, with sufferers often struggling to find healthcare providers who are familiar with IC/BPS [12, 26, 33, 35, 36, 41, 42]. Trivialising [27, 29, 30], feminization [30], stigmatisation [14, 30, 33], disbelief and rejection from doctors are reported [12, 31, 35]. The lack of knowledgeable physicians further complicates matters and exacerbates the sense of social stigma associated with the condition [33, 35].

4.2.1.3 | The Role of Relatives. The invisible nature of IC/BPS seems to lead to it being dismissed by family and friends [14, 27, 30–32, 34, 38, 41]. In addition, shame seems to prevent affected women from talking about their condition with family members [30, 35].

TABLE 4 | Extraction fields.

Extraction fields
(a) Author(s)/year of publication
Free text
(b) Source origin/country origin
Free text
(c) Aims/purpose/research questions
Free text
(d) Study population and sample size
Free text
(e) Methodology
(1) Qualitative methods
(2) Quantitative methods
(3) Systematic review
(4) Other review
(5) Unclear
(f) Stage of the illness experience
(1) Stage of Uncertainty
(2) Stage of disruption and crisis
(3) Stage of striving to regain self
(4) Stage of regaining wellness.
(g) Key findings which focus on the illness experience
Free text
(h) Inclusion of affected family of women with IC/BPS and significant others
(1) Yes
(2) No
(i) Perspective of information
(1) Patient perspective
(2) Expert perspective
(3) Family/significant others perspective
(4) Unclear

4.2.2 | Stage of Striving to Regain Self

Individuals with IC/BPS face significant challenges that severely impact their daily lives and drastic lifestyle changes.

4.2.2.1 | Losing a Normal Life. Uncertainty about the onset of symptoms restricts daily activities [28, 31, 32, 40, 41, 43], leading to the abandonment of enjoyable activities and hobbies, mourning their pre-IC/BPS life, and difficulties in performing routine tasks [31, 32, 34, 35]. Symptoms like frequent and urgent urination have a significant social impact, as sufferers often search for toilets constantly and may avoid leaving the house [25, 33, 35, 38, 41, 43]. This disruption to normality forces sufferers to plan activities rather than act spontaneously [35]. The stress and perceived burden on others can lead to social withdrawal, loneliness, and isolation [26, 30, 31, 41]. IC/BPS symptoms, especially frequent urination [40], can be humiliating and contribute to further social withdrawal of patients [25, 26, 28, 31–35, 38, 41].

Moreover, patients with IC/BPS experience stigma, including feeling like a sick spouse or bad mother, which affects their self-perception (as a woman) and interactions with others, further exacerbating the psychosocial challenges associated with the condition [25, 32, 33, 38].

4.2.2.2 | Effects on Employment. IC/BPS poses significant challenges in the workplace [26, 27, 29, 31–33, 41, 43], with concerns such as absenteeism and frequent bathroom breaks. Fear of losing their job is common among affected individuals, impacting their employment and financial stability [33, 35, 43]. Lack of empathy from coworkers and employers exacerbates the situation [14, 35]. IC/BPS can hinder job mobility, as individuals worry about new employers' understanding of the disease [34]. Many women with IC/BPS have given up work because of the persistent symptoms and the difficulty of managing them at work [32, 35, 38, 43].

4.2.2.3 | Sexual Health and Relationships. The impact of IC/BPS on sexual health and relationships is profound. Painful intercourse and fear of worsening symptoms are common issues that lead to a loss of intimacy and emotional distress [28, 32–34, 37, 38, 43, 44]. IC/BPS can also affect the sexual arousal of the healthy partner and lead to sexual activity being avoided or performed despite pain [34, 37, 38, 44]. Overall, IC/BPS affects both the emotional and physical aspects of intimacy and relationships, with anxiety and avoidance behaviours contributing to strain and complications in romantic relationships [25, 26, 28, 29, 31, 32, 34, 35, 37–39, 41, 43, 44].

4.2.2.4 | Family Dynamics. The impact of IC/BPS extends beyond individual patients to their families, resulting in increased responsibilities and feelings of sadness, frustration or helplessness [37, 38, 43]. Family dynamics are often disrupted [26, 27, 29, 41], requiring adjustments for tasks and activities [25, 31, 34, 38], with the patient's comfort becoming a constant consideration [39]. Difficulties may arise in dealing with the demands of children and grandchildren or parents' fears about their illness [34].

Family members may not fully comprehend the challenges of living with IC/BPS, leading to a reduction in social circles and friendships [30–32, 35].

If the partner and the family understand the woman's situation, this is described as a relief [25, 34, 38, 41]. Women with IC/BPS name their spouse as the best source of support [45].

4.2.2.5 | Emotions. Overall, the experience of IC/BPS is characterised by emotional distress, cognitive challenges, fear, and a desire for understanding and effective treatment.

Patients report emotional distress, including feelings of frustration, loneliness, isolation, upset, desperation, depression, anger, embarrassment, a sense of loss, suicidality, and increased body awareness [14, 25, 26, 29–31, 33, 34, 38, 41, 43]. They often experience complex emotions and concerns about others' lack of

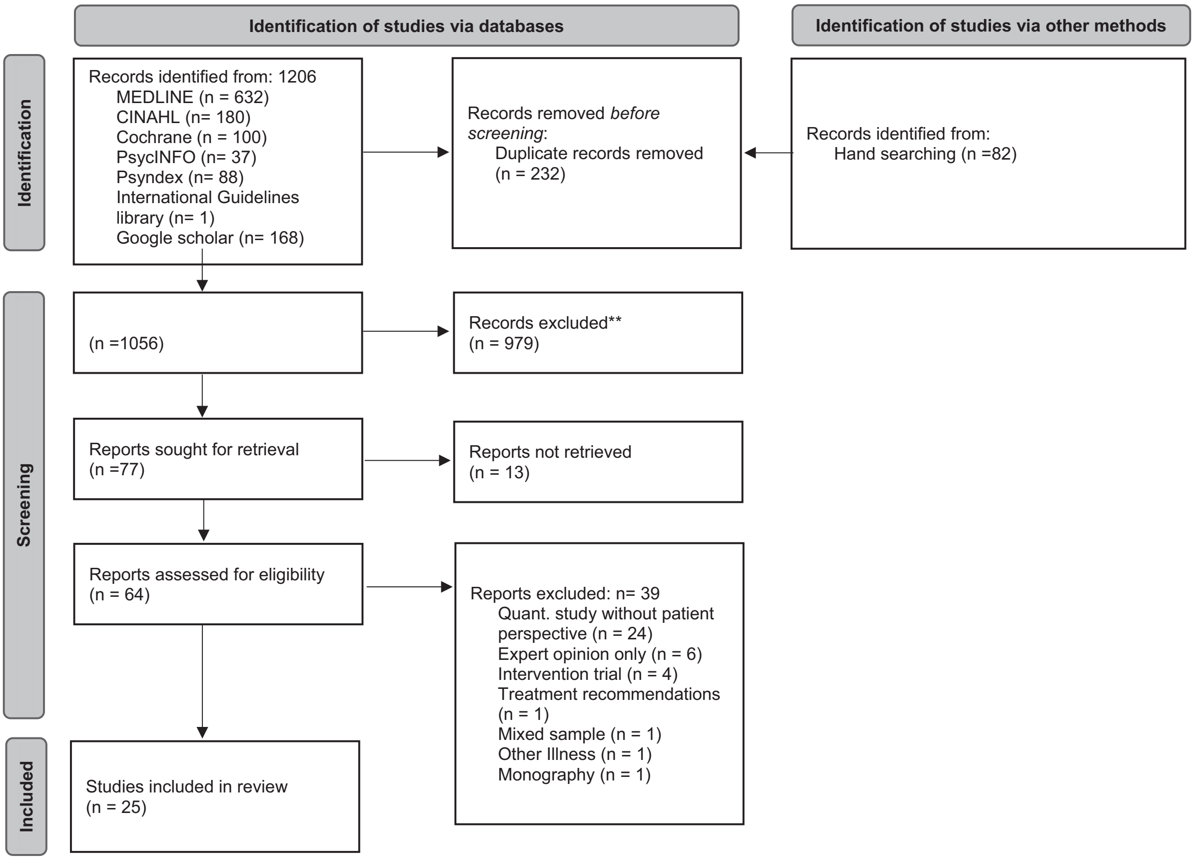

FIGURE 1 | PRISMA flow diagram of the literature search.

TABLE 5 | Country of origin and study design.

	Qualitative design	Mixed method design	Not clearly defined
Canada	Breau and Norman (2003) Butler et al. (2003)	Payne and Allee (2009) Volpe et al. (2021)	
Netherlands			Meijlink (2017)
UK	Kirkham and Swainston (2022)	Heyhoe and Lawton (2009) Windgassen et al. (2022)	
USA	Azedevo and Pyne (2001) Johnson and Johnson (2006) Kanter et al. (2017) McCormick and Vinson (1989)	Gonzalez et al. (2022) Gonzalez et al. (2019) Hassani et al. (2022b) Hayden et al. (2019) McCormick and Vinson (1988) McKernan et al. (2020) Sutcliffe et al. (2015) Webster (1997)	McCormick (1999) Slade et al. (1997) Webster (1996) Zakariasen and Hill (2009)
Taiwan		Chen et al. (2020)	

Note: 48% ($n = 12/25$) of the reviewed articles were published since 2015 (see Appendix C).

understanding of their illness, leading to social withdrawal and a significant psychosocial burden [26, 29, 31, 32, 39, 41].

There's a recognised cyclical relationship between emotional states and symptom severity, with distress both preceding and following symptoms [26, 38], leading to experiences of depression and emotional strain [35].

Patients commonly express fear of flare-ups and a fear of the future [25, 29, 31, 32, 43], including the continuous loss of quality

	Stage of Uncertainty	Stage of Disruption	Stage of Striving to Regain Self	Stage of Regaining Wellness
Azedevo & Pyne (2001)				
Breau & Norman (2003)				
Butler et al. (2003)				
Chen et al. (2020)				
Gonzales et al. (2019)				
Gonzales et al. (2022)				
Hassani et al. (2022)				
Hayden et al. (2019)				
Heyhoe & Lawton (2009)				
Johnson & Johnson (2006)				
Kanter et al. (2017)				
Kirkham & Swainston (2022)				
McCormick (1999)				
McCormick & Vinson (1988)				
McCormick & Vinson (1989)				
McKernan et al. (2020)				
Meijlink (2017)				
Payne & Allee (2009)				
Slade et al. (1997)				
Sutcliffe et al. (2015)				
Volpe et al. (2021)				
Webster (1997)				
Webster (1996)				
Windgassen et al. (2022)				
Zakariasen & Hill (2009)				

Figure 2: Allocation of evidence

FIGURE 2 | Allocation of evidence.

of life. They also hold onto fake hope for new treatments or a cure, which adds to their emotional burden [25, 31, 33].

The cognitive impact of IC/BPS is described as significant and includes excessive planning, preoccupation with symptoms, rumination and difficulty concentrating due to symptoms [28, 30, 35, 43].

4.2.2.6 | Health Belief.

Adapting and learning to live with the challenges of IC/BPS are described by Kirkham and Swainston (2022) as central to the women's experiences, which also appear to contribute to a change in their self-image [32]. Butler et al. (2003) also described that women often adopt the attitude that they are confronted with IC in their lives and that they simply have to learn to deal with it [25]. Chen et al. (2020) described it as 'coexisting with IC or feeling helpless' [28]. McCormick and Vinson (1989) reported that women with IC/BPS tell themselves that they have no choice but to deal with their condition and do their best to prevent IC/BPS from taking over their lives [34].

4.2.2.7 | The Treatment Experience.

Many women feel discouraged and frustrated with the treatment they receive and believe they must take a more active role in managing their treatment [25, 26, 42]. This involves researching extensively to stay informed about the latest developments in IC/BPS treatment options and being proactive in presenting research to medical professionals [25, 26, 32, 39, 42]. They experience undertreatment and overtreatment, lack of provider empathy, distrust in clinical recommendations, and the need for supplemental information to better understand IC/BPS [12, 14, 26, 29–34, 40, 42, 46].

Patients find it challenging to objectively track the fluctuating course of the disease, especially given the interactions between various symptoms, presenting barriers to expressing disease status accurately [33, 34, 40, 44].

Side effects such as diarrhoea, gastric ulcers, and odours are associated with treatments [25, 33, 37, 41]. This can lead to the desire to reduce medication [12, 41]. Fear of urological and gynaecological exams and invasive procedures can cause emotional distress and reduce some women's willingness to seek medical help [12, 32, 38].

Chen et al. (2020) categorised medical help seeking as 'exhaustion and frustration' always trying new medicines; and wasting time, money, and physical strength [28].

Patients desire increased awareness, research, and provider education in IC/BPS [12, 26, 42]. They emphasise the need for reliable patient education materials, integrated mental health services, structured support groups, individualised care plans and remote access to address both physiological and psychological aspects [12, 26, 31–33, 35, 40].

Dissatisfaction with treatment options and unwillingness to undergo certain treatments leads patients to seek self-management strategies [12, 26, 29, 31, 32, 36, 38, 40].

Managing multiple appointments and the difficulty of accessing treatment that requires multiple appointments place an additional burden on those affected [12].

The cost of treatment is sometimes described as a problem [29, 33, 36] that is further complicated by lack of cost coverage by health insurance companies [14, 25, 27]. Some women say they are grateful to have the necessary financial resources [38].

4.2.2.8 | Information Gathering, Self-Help and Coping Strategies.

Self-help groups (SHGs) are mentioned as a way of providing emotional support and to learn about living with IC/BPS [12, 25, 30, 34, 44], although studies indicate low utilisation by patients, often due to a lack of need or time constraints [25, 28, 45]. Seeking alternative therapies and learning from the experiences of others is emphasised as essential [29, 34, 36, 42].

Forums and online communities provide emotional support and information sharing for women with IC/BPS, complement their medical care and provide anonymity for honest communication [29, 32, 36].

Patients also seek knowledge from healthcare professionals, although it is noted that it is difficult to obtain comprehensive information from physicians [25, 26, 31, 42].

Women often experiment with treatments themselves to gain new knowledge about their condition [33]. Some individuals turn to literature to better understand IC/BPS [12, 26, 32, 42], especially after receiving treatments that may not be up to date. Despite efforts to find evidence-based information, many patients still feel inadequately informed about their options [25, 26, 32, 40, 42].

Various strategies highlight the multifaceted nature of self-help and coping with IC/BPS, for example dietary modifications [28, 30–34, 38, 43], staying close to bathrooms [25, 33, 38, 39, 43], distraction/diverting attention [28, 34, 43, 44], double voiding [28], social withdrawal/avoidance of social events [25, 26, 30–32, 35, 38, 41, 43], stress management [12, 38], and accepting and adapting to life with IC/BPS [12, 25, 28, 32, 34, 37, 38, 41, 44].

Patients differentiate between the goals of 'control' and 'decreasing symptoms', with control referring to the ability to make decisions about behaviours affecting symptom exacerbation [40].

4.2.2.9 | Prevent the Symptoms From Flaring Up. Women with IC/BPS often demonstrate self-awareness regarding factors that trigger flares, such as stress or dietary indiscretions, with flares being multifactorial and unique to each individual [31, 33, 38, 43, 46]. Flares range from mild discomfort to severe symptoms, hindering daily activities and confining patients to their homes or beds [43]. Trigger behaviours vary, including stress, sexual activity, alcohol, or dietary factors, with some individuals knowingly engaging in them despite potential consequences [38, 43, 46]. Flares are unpredictable for some of those affected [31, 32, 38, 43, 46] and lack of sufficient emergency medication increases anxiety [46]. Long-term impacts vary, with some experiencing anxiety and making lifestyle changes to avoid triggers [25, 29, 31, 32, 36, 38, 43, 46]. Strong flares can lead to suicidal ideation [31]. Overall, flares significantly affect patients' mental, emotional, and social well-being, with repercussions extending to spouses and family members, contributing to patients' stress levels [26, 31, 32, 38, 41, 43, 46].

4.2.3 | Stage of Regaining Wellness

Overall, recovery of well-being in IC/BPS is described by a combination of self-management strategies, partner support, individual coping mechanisms, and adjustments in physical activity and household management.

Some patients with IC/BPS empower themselves to cope despite periods of hopelessness [12]. Choosing supportive healthcare providers fosters trust [30, 34] and cooperation between them enables coordinated therapy [33, 35, 44]. Many patients shift from conventional treatments to dietary and lifestyle changes, focusing on body awareness, well-being, and stress reduction [32, 34, 38]. Various medical and non-medical interventions are experimented with to manage symptoms. Effective strategies include dietary regulation, muscle electrostimulation [34], stress reduction techniques, and bladder instillations, often combined to manage flare-ups [12, 25, 32, 43, 46].

Remembering religious beliefs, thinking about loved ones, engaging in interesting activities and accepting the illness [12, 25, 34, 38, 41] are also described as effective coping strategies. Better relationships with significant others are encouraged through open conversations about IC/BPS [25, 34, 37, 44], joking and self-disclosure [34, 37]. Some couples describe that coping with IC/BPS strengthens their relationship by improving communication, collaboration and intimacy [25, 34, 37, 38, 44]. For example, sexual activities are planned and expectations are reduced by finding new ways of intimacy together [34, 37, 44].

Staying physically active and keeping physically fit are other common strategies, although IC/BPS may require giving up hobbies or taking up new ones [30, 34, 38]. Help from family members or hired helpers may be needed to manage household tasks [34]. Avoiding stressful people and situations is emphasised as crucial to managing symptoms and maintaining overall well-being [34].

A constant wish of those affected is to increase the predictability of symptom worsening, as uncertainty is a constant companion [39, 40, 43].

5 | Discussion

This scoping review was able to provide an overview and insights into the existing evidence regarding the illness experience of women with IC/BPS.

It was shown that not all stages of the Illness Constellation Model according to Morse and Johnson [16] have been equally examined in scientific studies. It is striking that the «Stage of Uncertainty» has received less attention to date, with the existing literature highlighting that the time leading up to diagnosis appears to be particularly stressful and long. It is astonishing that uncertainty is emphasised in the first phase of the illness constellation model, but its significance as a constant companion in the course of the disease. One explanation for that could be, that the challenges faced in the different stages of the model tend to recure. The illness constellation model alone may be insufficient as an explanatory approach. Future research should therefore reconstruct the uncertainty in the course of the illness with its crisis-like transitions, stable and unstable phases in the sense of the trajectory work model according to Corbin and Strauss [47, 48] and the associated coping behaviour. Early identification of those affected could alleviate suffering and help establish treatment strategies before significant life quality declines.

Women with IC/BPS experience physical, psychosocial, and cognitive challenges that impact both their own lives and their families, with Grypdonck highlighting that chronic illness affects family members just as much as the individuals suffering from the condition [8]. The identified publications offer limited information on the family system and the perspectives of affected individuals regarding their future family life. There is a lack of insight into family interactions or specific coping strategies. Additionally, the impact on partnership and sexuality raises unresolved questions about whether relationship failures or higher divorce rates are more common.

The presentation of symptoms and their impact on employment suggest that affected women may face reduced career opportunities. However, no evidence supporting this assumption was found in the literature.

Some studies excluded women who were, for example, already in remission or experiencing acute emotional distress. However, these individuals would have been of interest in our scoping review to capture the illness experience across all stages and conditions of the illness trajectory.

Recovery of well-being in IC/BPS is linked to self-management, partner support, coping mechanisms, and adjustments in daily activities, rather than pharmacological or surgical treatment. Affected individuals seek support and knowledge about self-management, underscoring the need to empower women and involve family members, especially partners, as resources. However, the meaning of self-management and successful strategies from the women's perspective remain unclear.

Since most identified studies are situated within Anglo-American healthcare systems, the question arises as to whether the healthcare system influences the illness experience of affected individuals. Joacham et al. provide insights into the situation in Germany, showing that IC/BPS patients wait an average of 9 years for a diagnosis [49].

The screening revealed that transparency in research methods is key to understanding meaningful data on illness experience. Studies using only quantitative designs provided purely descriptive insights, lacking depth on experiences, beliefs, processes, or interactions. Mellado et al. (2019) examined the use of qualitative research in female pelvic pain, including IC/BPS, highlighting its importance for understanding women's experiences and suggesting it can improve multidisciplinary management [50]. The complexity and multidimensionality of IC/BPS suggest that individualised and flexible intervention strategies are necessary to address the needs of those affected. Höhmann also confirms that, based on knowledge of the affected life domains and the coping efforts of patients, needs for interventions can be identified and responsibilities within integrated care can be defined [51].

Scoping reviews do not assess the quality of the included studies. Therefore, it must be mentioned that the publications differ significantly in the quality of their reporting, especially the information on methodology. The main advantage of including all publications, regardless of their reporting quality, was to include as many sources of knowledge as possible. This was particularly important, as few sources go beyond the purely quantitative consideration of the situation of those affected.

As in every review, publications may not have been identified despite a very carefully conducted literature search.

6 | Conclusion

This scoping review contributes to structuring the existing evidence on the illness experience of women with IC/BPS in a transparent way.

As already described, recommendations for practice can only be made to a limited extent. In terms of content, two implications for practice can be emphasised: Raising awareness and disseminating information about IC/BPS among healthcare professionals and providing tailored support for successful coping and self-management for those affected and their family members.

Future research activities should strive for a deeper understanding of the illness experience and self-management of those affected. Attention should be paid to the facilitating and hindering factors. A theoretical framework for orientation is indispensable.

Author Contributions

Jennifer Enaux and **Michaela Sorber:** study design, data collection, analysis, manuscript preparation. **Adergicia Vitorio Kaiser:** analysis, manuscript preparation. **Christiane Knecht:** study design, analysis, manuscript preparation.

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Disclosure

This research work is part of a dissertation (thesis) project.

Ethics Statement

No research ethics concerns are involved in a scoping review; therefore, no ethical clearance was obtained. The results of the scoping review will be used to further refine the topic of the illness experience of IC/BPS and identify research gaps. The resulting research questions will be explored in the following empirical study.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Appendix A

Attachment 2: Descriptive Mapping Characteristics

Table based on the Illness Constellation Model according to Morse and Johnson [16, 315–338, 321, fig. 7.3].

Stage of the Illness Constellation Model according to Morse and Johnson [16]	Descriptive mapping characteristics
Stage of uncertainty	The individual (self) detects or suspects signs of illness and attempts to make sense of these symptoms by determining their severity and meaning. • Suspecting • Reading the body • Being overwhelmed Those closest to the ill person (others) • Observe that the sick person is unwell • Suspecting • Monitoring • Are overwhelmed
Stage of disruption	The individual (self) • Decides that the illness is real • Decides to seek help • Relinquishes control and withdraws by distancing him- or herself from the situation • Becomes dependent on health care professionals and family members Those closest to the ill person (others) • Become aware of the illness and the threat • May hover • Are vigilant • Suffer with the individual • Assume the day-to-day responsibilities of the ill person Typical events • Confirmation of a medical diagnosis • Medical emergency (immediate action)
Stage of striving to regain self	The individual (self) • Makes sense of the illness • Examines the past for reasons that explain the illness • Tries to predict the future ramifications of the illness • Preserves self (conserving and focusing energy) • Renegotiates roles (self-identity, control) • Sets goals • Seeks reassurance Those closest to the ill person (others) • Commit to the fight/struggle • Endure the illness process • Buffer (reduce stimuli and protect the sick person from undue stressors) • Renegotiate roles • Monitor activities • Work and assist with treatments and day-to-day tasks • Monitor and modify the sick person's goals (realistic and achievable) • Support and encourage the individual
Stage of regaining wellness	The individual (self) • Attains mastery • Takes charge • Determines when he or she is 'better' • Accepts a changed level of functioning • Monitors symptoms closely Those closest to the ill person (others) • Assist the ill person in making it through • Provide support and allowing the ill person to gradually regain control of his or her life

Appendix B

Citation	Reason for exclusion
Baldwin, C. M., & Herr, S. W. (2004). The impact of self-care practices on treatment of interstitial cystitis. *Urologic nursing*, 24(2), 107–113.	Intervention trial
Bradley, Catherine S.; Gallop, Robert; Sutcliffe, Siobhan; Kreder, Karl J.; Lai, H. Henry; Clemens, J. Quentin; Naliboff, Bruce D. (2022): Long-Term Symptom Trajectories in Urologic Chronic Pelvic Pain Syndrome: A MAPP Research Network Study. In: *Urology* 169, S. 58–64. https://doi.org/10.1016/j.urology.2022.07.045.	Quantitative survey on symptom prevalence without qualitative data from the perspective of those affected.
Di Giacomo, D., Ranieri, J., Nasta, L., Moscato, S., Guerra, F., & Passafiume, D. (2019). Psychological distress in Interstitial Cystitis/Bladder Pain Syndrome: A cross-sectional study on emotional patterns. Advance online publication. https://doi.org/10.6092/2282-1619/2019.7.2135	Quantitative survey on symptom prevalence and QoL without qualitative data from the perspective of those affected.
Draucker C. B. (1991). Coping with a difficult-to-diagnose illness: the example of interstitial cystitis. Health care for women international, 12(2), 191–198. https://doi-org/10.1080/07399339109515940	Expert opinion only
Garba, K., Avery, M., Yusuh, M., Abdelwahab, O., Harris, S., Birch, B. R., & Lwaleed, B. A. (2021). The relationship between illness perception and worsening of interstitial cystitis/painful bladder syndrome symptoms: A cross-sectional study. *Neurourology and urodynamics*, 40(8), 2020–2025. https://doi-org/10.1002/nau.24787	Quantitative survey on symptom prevalence without qualitative data from the perspective of those affected
Gordon, A. S., Panahian-Jand, M., Mccomb, F., Melegari, C., & Sharp, S. (2003). Characteristics of women with vulvar pain disorders: responses to a Web-based survey. *Journal of sex & marital therapy*, *29 Suppl 1*, 45–58. https://doi.org/10.1080/713847126	Quantitative survey, mixed sample without the possibility of analysing IC/BPS as a subgroup
Gotoh M, Kobayashi T, Sogabe K. Characterisation of symptom bother and health-related quality of life in Japanese female patients with overactive bladder. *Neurourol Urodyn*. 2015 Nov;34(8): 730–5. https://doi.org/10.1002/nau.22663. Epub 2014 Sep 11. PMID: 25212503.	Disease other than IC/BPS
Hawkey, A., Chalmers, K. J., Micheal, S., Diezel, H., & Armour, M. (2022). "A day-to-day struggle": A comparative qualitative study on experiences of women with endometriosis and chronic pelvic pain. *Feminism & Psychology*, 32(4), 482–500. https://doi.org/10.1177/09593535221083846	Mixed Sample and minimal number of IC/BPS
Jocham, B. (2012). Lebensbilder von Frauen mit Interstitieller Cystitis: Emotionale und kognitive Faktoren als modifizierende Elemente bei der Entstehung, Aufrechterhaltung und Reduktion chronischer Schmerzen am Beispiel IC/BPS. Zugl.:@ Hamburg,Univ.,Diss.,2012 (1., Aufl.). Berichte aus der Psychologie. Aachen: Shaker.	Monografie
Jocham, D.; Froehlich, G.; Sandig, F.; Ziegler, A. (2013): Die Versorgungssituation von Patienten mit interstitieller Zystitis in Deutschland: Ergebnisse einer Umfrage unter 270 Betroffenen. In: *Der Urologe. Ausg. A* 52 (5), S. 691–702. https://doi.org/10.1007/s00120-013-3130-8.	Description of patient care without qualitative data from the perspective of those affected.
Katz, L., Tripp, D. A., Carr, L. K., Mayer, R., Moldwin, R. M., & Nickel, J. C. (2017). Understanding pain and coping in women with interstitial cystitis/bladder pain syndrome. *BJU international*, 120(2), 286–292. https://doi-org/10.1111/bju.13874	Quantitative survey on symptom prevalence without qualitative data from the perspective of those affected.
Katz, Laura: A self-regulatory model of coping in women with interstitial cystitis/bladder pain syndrome.	Quantitative evaluation of coping strategies without qualitative data from the perspective of those affected.
Katz, L., Tripp, D. A., Nickel, J. C., Mayer, R., Reimann, M., & van Ophoven, A. (2013). Disability in women suffering from interstitial cystitis/bladder pain syndrome. *BJU international*, 111(1), 114–121. https://doi-org/10.1111/j.1464-410X.2012.11238.x	Statistical model of coping strategies without qualitative data from the perspective of those affected.
Kaufman, M. W., All, A. C., Hall, N., & Clark, J. Y. (1997). Caring for the patient with interstitial cystitis. *Medsurg nursing: official journal of the Academy of Medical-Surgical Nurses*, 6(4), 203–208.	Expert opinion only
Kim, Su Jin; Kim, Jayoung; Yoon, Hana (2019): Sexual pain and IC/BPS in women. In: *BMC urology* 19 (1), p. 47. https://doi.org/10.1186/s12894-019-0478-0.	Quantitative investigation of co-morbidity vulvodynia without qualitative data from the perspective of those affected.
Kuhn, A., Schmid, C., & Mueller, M. D. (2008). Quality of Life and Sexual function in women with interstitial cystitis. *Geburtshilfe Und Frauenheilkunde*, 68(S 01). https://doi.org/10.1055/s-0028-1088571	Intervention trial

Citation	Reason for exclusion
Lin, K. B.-S., Wu, M.-P., Lin, Y.-K., Yen, Y.-C., Chuang, Y.-C., & Chin, H.-Y. (2021). Lifestyle and behavioural modifications made by patients with interstitial cystitis. *Scientific Reports*, *11*(1), 3055. https://doi.org/10.1038/s41598-021-82676-5	Quantitative evaluation of coping strategies without qualitative data from the perspective of those affected
Meriwether, K. V., Panter, V., McWethy, M., Rishel Brakey, H., & Komesu, Y. M. (2022). Centering Group Treatment for Women With Interstitial Cystitis/Bladder Pain Syndrome: A Qualitative Analysis. *Urogynecology* (Philadelphia, Pa.), 28(10), 695–704. https://doi-org./10.1097/SPV.0000000000001228	Intervention trial
Mishell, D. R. (2004): Chronic Pelvic Pain in Women: focus on the bladder. *Journal of reproductive medicine* 49 (3, Suppl.), 223–224.	Treatment recommendations
Nickel, J. C.; Tripp, D.; Teal, V.; Propert, K. J.; Burks, D.; Foster, H. E. et al. (2007): Sexual function is a determinant of poor quality of life for women with treatment refractory interstitial cystitis. In: *Journal of urology* 177 (5), S. 1832–1836. https://doi.org/10.1016/j.juro.2007.01.060.	Quantitative survey on symptom prevalence
Rabin, C.; O'Leary, A.; Neighbours, C.; Whitmore, K. (2000): Pain and depression experienced by women with interstitial cystitis. In: *Women & health* 31 (4), S. 67–81. https://doi.org/10.1300/j013v31n04_05.	Quantitative survey on symptom prevalence
Rothrock, N. E., Lutgendorf, S. K., Hoffman, A., & Kreder, K. J. (2002). Depressive symptoms and quality of life in patients with interstitial cystitis. *The Journal of urology*, 167(4), 1763–1767.	Quantitative survey on symptom prevalence, qualitative data not reported
Rothrock, N., Lutgendorf, S. K., & Kreder, K. J. (2003). Coping strategies in patients with interstitial cystitis: relationships with quality of life and depression. *The Journal of urology*, 169(1), 233–236. https://doi-org./10.1016/S0022-5347(05)64075-X	Quantitative survey on symptom prevalence without qualitative data from the perspective of those affected.
Simon, L. J., Landis, J. R., Erickson, D. R., & Nyberg, L. M. (1997). The Interstitial Cystitis Data Base Study: concepts and preliminary baseline descriptive statistics. *Urology*, 49(5A Suppl), 64–75. https://doi-org/10.1016/s0090-4295(99)80334-3	Quantitative survey on symptom prevalence without qualitative data from the perspective of those affected.
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Wang, J. W., Liu, J. C., Meng, L. F., Zhang, W., Liu, X. D., & Zhang, Y. G. (2021). [Quality of life and related factors in patients with interstitial cystitis/bladder pain syndrome]. Journal of Peking University. *Health sciences*, 53(4), 653–658. https://doi.org/10.19723/j.issn.1671-167X.2021.04.005	Quantitative evaluation of coping strategies without qualitative data from the perspective of those affected. Publication in a foreign language.
Warren, J. W. (2007): Interstitial Cystitis/Painful Bladder Syndrome. *Urologic Nursing* 27(3), 185–190.	Expert opinion, focus on diagnostics and therapy (including nutrition etc.)
Webster, D. C., & Brennan, T. (1995). Self-care strategies used for acute attack of interstitial cystitis. *Urologic nursing*, 15(3), 86–93.	Quantitative evaluation of self-care strategies without qualitative data from the perspective of those affected
Webster, D. C. (1990): Comparing patients' and nurses' views of interstitial cystitis: a pilot study. In: *UNJ* 10 (3), S. 10–15.	Quantitative evaluation without qualitative data from the perspective of those affected

Citation	Reason for exclusion
Webster D. C., Brennan T. (1995): Use and effectiveness of psychological self-care strategies for interstitial cystitis. *Health Care Women Int*. 1995 Sep-Oct;16(5):463–75. https://doi.org/10.1080/07399339509516199	Quantitative survey on symptom prevalence without qualitative data from the perspective of those affected.
Wenstrup, Thomas MD; Seneewong, Tana MD; Liu, Aiwen MD. Does a diet change improve symptoms of interstitial cystitis?. *Evidence-Based Practice* 22(12):p 27–29, December 2019. https://doi.org/10.1097/EBP.0000000000000481	Quantitative investigation of the impact of changes in dietary behaviour without qualitative data from the perspective of those affected.
Whitmore, K. E. (1994). SELF-CARE REGIMENS FOR PATIENTS WITH INTERSTITIAL CYSTITIS. *Urologic Clinics of North America*, 21(1), 121–130. https://doi.org/10.1016/S0094-0143(21)00601-7	Expert opinion only
Yeung, Jennifer Y.; Eschenbacher, Michaela A.; Pauls, Rachel N. (2014): Pain and embarrassment associated with urodynamic testing in women. In*: International urogynecology journal* 25 (5), S. 645–650. https://doi.org/10.1007/s00192-013-2261-1.	Quantitative study about feeling of embarrassment during urodynamics without qualitative data from the perspective of those affected.
Zambon, J., Hemal, K., Evans, R., Badlani, G., Walker, S., Plair, A., … Matthews, C. (2019). MP47-18 SIMPLE CYSTECTOMY FOR FEMALE PATIENTS WITH REFRACTORY INTERSTITIAL CYSTITIS/BLADDER PAIN SYNDROME: IS THERE ANY LONG-TERM IMPACT ON QUALITY OF LIFE, BODY IMAGE, AND SEXUAL FUNCTION? *Journal of Urology*, 201(Supplement 4), e695. https://doi.org/10.1097/01.JU.0000556482.45742.4b	Intervention trial
Choosing method is difficult for women with bladder disorder. (1993). *Contraceptive technology update*, 14(10), 157–160. (No authors listed)	Expert opinion only

Appendix C